

Institution: Newcastle University
Unit of Assessment: 28 Modern Languages and Linguistics
Title of case study: The importance of communication change over time: Influencing practice in the management of people with Parkinson's disease
<p>1. Summary of the impact</p> <p>The underpinning research delivered the first concrete and specific insights into service organisation, content and provision for people with Parkinson's (pwP). As a result, the research has been able to directly influence and inform government and professional body aims, policies and guidelines, and inform educational and clinical practice. The research has therefore contributed to the wellbeing of pwP in the UK and across Europe. Parkinson's disease is a degenerative neurological disorder which is estimated to affect 6.3 million people worldwide, including 1.2 million people across Europe and 120,000 people in the UK. Most pwP experience negative changes to their voice, speech, language and swallowing.</p>
<p>2. Underpinning research</p> <p>This case concerns a novel programme of research into the previously neglected psychosocial consequences of communication and swallowing changes in Parkinson's and the implications these have for treatment/support of pwP. Prior to 2000 acoustic and movement aspects of changes to speech were relatively well characterised, though little empirical research had addressed the vital issues around the impact of changes on intelligibility and eating/drinking and communication and swallowing related quality of life. This programme, led by Nick Miller (Professor of Motor Speech Disorders, 1994-current), placed pwP at the centre of research by describing and quantifying the functional, psychosocial consequences of motor and cognitive changes in pwP. The results were then applied to the improvement and development of speech-language pathology and other services to support pwP.</p> <p>Publications have filled key gaps in the international literature on aspects of communication change in Parkinson's and its impact on individuals and families (1-6). The research was the first to show that, even in pwP who score apparently in the 'normal' range on clinical screening tests, and so would not have been offered support, there are significant perceived changes that can impact greatly on the life of the pwP and their family (4). Furthermore, the research highlighted that one cannot infer from scores on basic motor/physiological tests of speech and communication what the impact of changes might be (3, 4). Two key strands of work over the past 10 years underpin the wider research programme: (i) The first ever detailed large scale community based studies in the world of communication and swallowing changes in people with Parkinson's was carried out to establish the extent and nature of changes in these neglected areas (3, 4); (ii) The first detailed investigation of speech-language therapy services for people with Parkinson's was undertaken, covering not just the researcher and clinicians' perspective but crucially also that of users (5, 6). These quantitative studies were complemented by the first ever large-scale in-depth qualitative studies investigating the impact of communication and swallowing changes from the point of view of pwP (1, 2). The studies delivered the first tangible and specific insights into service organisation, content and provision for pwP.</p> <p>The studies delivered novel, fundamental data for the wider Parkinson's research and clinical community worldwide, charting changes in speech/swallowing and the relationship of changes to progression of symptoms in other aspects of Parkinson's. The most significant findings of the research that have gone on to have greatest impact concern the psychosocial impact of changes and the major implications for intervention and support services for pwP. Completing this research has entailed development and standardisation of assessments of intelligibility and impact for use in clinic with people with Parkinson's and with motor speech disorders more generally. Drawing on research insights, Miller is engaged with national and international drivers for clinical change. Out of the initial work have grown important further strands of investigation and engagement. The research was the first to chart longitudinal evolution of functional impact of communication changes on the individual with Parkinson's. Studies completed or underway are focusing on specific aspects of communication change: e.g. alterations to voice and intonation; relationship of depression and</p>

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speech changes in people with Parkinson's; characterisation and quantification of vocal tremor in people with Parkinson's; use of speech assessments in the differentiation of Parkinson's from related disorders; evaluation of treatment approaches for voice/speech and for swallowing/drooling. The core team is led by Miller with colleagues David Burn (neurology), Emma Noble (health services research) and Anna Jones (health services research and physiotherapy).

3. References to the research

1. Miller N., Noble E., Jones D., Burn D. (2006) Life with communication changes in Parkinson's disease, *Age and Ageing*, 35, 235-39. doi:10.1093/ageing/afj053
2. Miller N., Noble E., Jones D., Burn D. (2006) Hard to swallow: dysphagia in Parkinson's disease, *Age and Ageing*, 35, pp614-18. doi: 10.1093/ageing/af1105
3. Miller N., Allcock L., Jones D., Noble E., Hildreth A.J., Burn D. (2007) Prevalence and pattern of perceived intelligibility changes in Parkinson's disease, *J Neurology, Neurosurgery, Psychiatry*, 78, 1188-90. doi:10.1136/jnnp.2006.110171 [*Voted best article by patient readers]
4. Miller N., Noble E., Jones D., Allcock L., Burn D. (2008) How do I sound to me? Perceived changes in communication in Parkinson's disease *Clinical Rehabilitation*, 22, pp14-22. doi: 10.1177/0269215507079096
5. Miller N., Noble E., Jones D., Deane K., Gibb C. (2011) Survey of speech and language therapy provision for people with Parkinson's disease in the United Kingdom: patients' and carers' perspectives, *International Journal of Language and Communication Disorders*, 46, pp179-188. doi: 10.3109/13682822.2010.484850 [*Awarded the editors' runner up prize in the annual best article competition]
6. Miller N., Deane K., Jones D., Noble E., Gibb C. (2011) National survey of speech and language therapy provision for people with Parkinson's disease in the United Kingdom: therapists' practices, *International Journal of Language and Communication Disorders*, 46, pp189-201. doi: 10.3109/13682822.2010.484849

The programme has entailed large scale original studies, both quantitative and qualitative, employing rigorous methodological designs, published in key high impact journals in the fields of neurology, gerontology/health care of the elderly and speech language pathology.

Key grant information:

Principal Investigator	Grant Title	Sponsor	Period	Total Grant
Nick Miller	Prevalence, nature and psychosocial impact of speech voice & swallowing changes in PD. A community study	Parkinson's Disease Society	2003 to 2005	£81,000
Nick Miller	Longitudinal changes in speech and swallowing disorders in PD	Parkinson's Disease Society	2006	£10,000
Nick Miller	A national survey of speech language therapy provision for people with PD: therapists' practices, patients' & carers' perspectives	Parkinson's Disease Society	2006 to 2008	£73,000

4. Details of the impact

The underpinning research delivered the first concrete and specific insights into service organisation, content and provision for pwP. Crucially, the research has been able to directly influence and inform government and professional body aims, policies and guidelines, as well as contributing to the education and training of professionals. The research has also informed resources for pwP and their carers. The research has therefore contributed to the wellbeing of pwP in the UK and across Europe.

Influencing and Informing Government and Professional Body Aims, Policies and Guidelines

Drawing on research findings, the lead researcher Miller has presented evidence to parliamentary enquires and committees. For example, as a result of giving evidence to the All Party

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Parliamentary Group (APPG) for Parkinson's Disease, the research was cited multiple times in the final report on Parkinson's Disease services. This report identified significant barriers and inequalities in service access and made a number of key recommendations. Research insights were used to provide evidence in relation to palliative and end of life care, inadequacies in the experience and expertise of key professionals, including training issues, and inequalities in access to speech and language therapy provision. For example, the report states "*Dr Nick Miller provided evidence about the importance of seeing patients from the point of diagnosis to prevent, or delay, many serious complications that may be experienced by people in the later stages of Parkinson's disease, such as swallowing problems and malnutrition, as well as speech problems. However his research findings highlighted major shortfalls in preventative interventions*" (pp8-9) **(IMP1)**.

As a result of the research, Miller has been invited and appointed to join key committees. For example, in 2009 Miller was invited to join a committee to oversee the implementation of National Institute for Health and Clinical Excellence (NICE) Guidelines for Parkinson's UK (PUK) (a national patient advocacy organisation). He was also invited onto a further audit steering committee that was set up to implement, in cooperation with professional bodies (e.g. Royal College of Speech and Language Therapists (RCSLT); British Geriatric Society), an annual national audit of services of the management of pwP to monitor change in services. The annual audits help healthcare organisations measure their services against NICE guidelines and aids them in improving and developing their services for pwP, as part of the wider improvement agenda. Miller had direct input into the audit tools for medical services, which drew directly from the underpinning research process. Leading figures from PUK confirmed that "*We were able to draw directly on Nick Miller's research and input to achieve this. This tool has in the meantime been fully implemented across the NHS and is delivering valuable data for Parkinson's UK in driving up standards of services for people with Parkinson's and has been praised by users as a tool that directly facilitates review and improvement of their clinical services*" **(IMP2)**. Following the success of the above tool, Miller was also selected as specific lead for the speech-language therapy tool and "*his research work in already conducting national surveys of service user and provider issues for people with Parkinson's was invaluable in this respect*". The SLT tool "*has received very positive feedback as a method to benchmark and improve services*" **(IMP2)**.

Findings from the research have been incorporated into guidelines nationally and internationally. The Scottish Intercollegiate Guidelines Network (SIGN), which develops evidence-based clinical practice guidelines for NHS Scotland, cited the research in its national clinical guideline (2010) in the sections on Communication and Non-Motor Symptoms **(IMP3)**. The Dutch ParkinsonNet (Dutch patient advocacy organisation) guidelines, which are highly regarded internationally, draw on the research to provide support for everyday clinical practice. Citing the research findings, the guidelines highlight the need for more in-depth assessments beyond the sole use of checklists, as Parkinson's can have an impact on swallowing and communication behaviour even if the patient looks like they are doing satisfactorily on the surface **(IMP4)**. The relevance of the research to clinical practice is also reflected in Miller's role as national advisor to the RCSLT. RCSLT's Head of Professional Development confirmed that: "*[Miller] has supported the work of the RCSLT over many years and his research work continues to have an impact on clinical practice. He made a significant contribution to 'Communicating Quality 3' (the RCSLT's professional standards publication) by authoring/co-authoring three chapters. Whilst published in 2006 this continues to support the practice of the SLT profession [...] Through his role as national adviser for acquired neurological disorders (in particular motor speech disorders), he regularly provides up to date, evidence based information to our members. This information supports clinical decision making in practice. Professor Miller is contacted regularly on behalf of our members due to his in-depth knowledge and expertise in his field*" **(IMP5)**.

Contributing to Education and Training of Professionals and Informing Resources for pwP

Insights from the research have been used to inform education, training, clinical practice and resources for pwP. For example, Miller used the research to contribute to the British Medical Journal Continuing Medical Education Programme, *BMJ Learning*, on the module 'Common Speech and Language Disorders in Adults: an Overview'. This module is taken by a wide range of medical professionals and is accredited by Professional Bodies worldwide, for example, the

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Austrian Academy of Physicians and the Royal New Zealand College of General Practitioners **(IMP6)**. An Erasmus project has used research findings as recommendations for teaching programme content and benchmarks in Speech Language Therapy courses in Europe, such as a post-qualifying specialisation course, 'European Clinical Specialisation in Motor Speech Disorders' **(IMP7)**. Drawing directly on the research, Miller has delivered webcasts and podcasts. For example, his video podcast for healthcare professionals on the Special Interest Group Neurology section of the GlaxoSmithKline website offers an overview of the types and extent of changes in communication associated with Parkinson's and outlines some issues and practices in intervention to support people with Parkinson's who experience such changes **(IMP8)**. Miller has also been invited to address/train colleagues on the issues at workshops in many countries.

The research has informed the content of publications and services to support both professionals and pwP. Several PUK information sheets which focus on swallowing, saliva control, communication, speech, voice and language, drew on the research and are available in hard copy for clinics and online for professionals and service users worldwide **(IMP2,9)**. Pre-eminence of the work and Miller's international expertise in this field was also acknowledged in late 2010 when he was chosen to be the 'resident' expert on the PUK web-based 'ask the expert' site where people from around the world can write in with their questions about any aspects of the field **(IMP2,10)**. Miller has also been involved in several radio and TV broadcasts in the UK and other countries around the topic of communication and swallowing changes.

5. Sources to corroborate the impact

- (IMP1) All-Party Parliamentary Group for Parkinson's Disease (2009) *Please Mind the Gap: Parkinson's Disease Services Today*, Inquiry into Access to Health and Social Care services for People with Parkinson's Disease and their Carers (pgs 3, 5-6, 8, 13-15, 28).
- (IMP2) Factual Statement by Director of Research and Innovation, and Head of Professional Engagement and Education (co-signed), Parkinson's UK (PUK).
- (IMP3) SIGN (2010) *Diagnosis and Pharmacological Management of Parkinson's Disease: A National Clinical Guideline*, Edinburgh: SIGN (pgs 6, 8, 56).
- (IMP4) H Kalf et al (2008) *Logopedie bij de ziekte van Parkinson: Een richtlijn van de Nederlandse Vereniging voor Logopedie en Foniatrie (Speech Therapy in Parkinson's Disease: Guidelines from the Dutch Speech Language Therapists and Phoniatics Union)*, Association of the Hague: Lemma Publishing. (In Dutch, pgs 12, 55, 66, 76, 95, 96, 149).
- (IMP5) Factual Statement by Head of Professional Development, RCSLT.
- (IMP6) BMJ Learning Module 'Common Speech and Language Disorders in Adults: an Overview', contribution by Miller. Available at: http://learning.bmj.com/learning/module-intro/common-speech-language-disorders-adults.html?locale=en_GB&moduleId=10020642
- (IMP7) Education, Audiovisual and Culture Executive Agency (2009) *European Clinical Specialisation in Motor Speech Disorders, Final Report, Public Part*. Available at: http://eacea.ec.europa.eu/llp/project_reports/documents/Erasmus/erasmus_2007_final_reports/ecd-2007-133920-fr.pdf.
- (IMP8) Video podcast for health professionals, on GSK website. Available at: <http://hcp.gsk.co.uk/therapy-areas/neurology/gsk-scinapse-promotional-webcasts-and-videos/helping-people-wit-parkinsons.html>
- (IMP9) PUK Information Sheets in the Symptoms and Lifestyle series: *Communication and Parkinson's* (2012) (Miller is cited as one of contributors); *Eating and Swallowing and Saliva Control in Parkinson's* (2011) (research is cited).
- (IMP10) Transcript of 'Q&A: Speech and Language Problems in Parkinson's', PUK. Available at: http://www.parkinsons.org.uk/advice/question_and_answer_qa_sess/qa_speech_and_language.aspx